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Individualizing Care for Pediatric Patients with Autism Spectrum Disorder in Perioperative Services

Erin Scheller
eescheller@dons.usfca.edu

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University of San Francisco

Abstract

This research explores solutions for individualizing and improving care for pediatric patients with Autism Spectrum Disorder in the Perioperative Setting of an Outpatient Surgery Center. Specifically, it seeks to determine if providing parent and staff resources on Autism Spectrum Disorder is significantly helpful in increasing confidence in the staff by the parents and the staff themselves. Participants included thirty-five surveyed families who had pediatric patients visiting perioperative services and staff who work on the unit. Methods used include information dissemination with the use of printable and online evidence-based resources, an in-person education event for staff, and a pilot study of a parent questionnaire. Data collection showed that 72.7% of families thought that staff was better prepared to care for their child due to the piloted parent questionnaire. Additionally, of the staff that provided feedback after the in-service ASD education event, the majority indicated that their confidence in preparedness in caring for children with behavioral diagnoses was improved. Overall, this paper shows that an increase in staff and family confidence in staff's ability to care for patients with Autism Spectrum Disorder did improve after project implementation.

Individualizing Care for Pediatric Patients with Autism Spectrum Disorder in Perioperative Services

Pediatric Patients with Autism Spectrum Disorder (ASD) often pose unique challenging for staff in perioperative services. Because this group of patients is diverse and low-frequency, many nurses and other staff members do not feel confident preventing or handling their potentially challenging behavior. Additionally, the perioperative environment is especially overwhelming for some patients, and can be an overstimulating place for many patients living with ASD. Lack of individualized care for children with various behavioral diagnoses has resulted in interrupted workflow within the perioperative department of a local state-funded children's hospital outpatient surgery center. In 2017, 17.8% of patients seen in the outpatient center had a behavioral diagnosis, which may include ASD. This set of patients reportedly causes surgical delays due to communication deficits, lack of staff training, and inadequate identification of ASD symptoms. Surgical delay and interrupted workflow results in unnecessary cost for the hospital and poor patient satisfaction results, as well as a safety concern for patients and staff. A group of students from the University of San Francisco, including the author, set out to provide solutions for this problem. Specifically, we aim to provide specialized training for nurses, to disseminate information for parents and families regarding their children in the perioperative setting, to create a clinical reference document for staff to use when encountering a patient with ASD, and to implement a pre-procedure family questionnaire to help recognize and assess the individual needs of all patients.

Literature Review

In order to fully understand the extent of influence that Autism Spectrum Disorder has on the Perioperative environment and experience for patients, families, and staff, the team conducted a literature review of available research. Databases including CINAHL, PubMED, and Cochrane produced results with keyword and subject searches. Generally, there is a noted lack of research available on pediatric Autism Spectrum Disorder, as described by Damiano, Mazefsky, White, and Dichter (2014), especially as rates of diagnosis increase rapidly. However, the future of ASD research is promising and ongoing (Damiano et al., 2014). The available data does point to interesting conclusions regarding pediatric patients and the perioperative environment and provided some useful solutions for practitioners and families.

Pediatric Autism Spectrum Disorder

According to a 2014 study published by the United States Centers for Disease Control and Prevention, ASD is a developmental disability defined by its "deficits in communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life" (Baio et al., 2014). According to the same study, one in 59 children in the United States is diagnosed with Autism Spectrum Disorder using DSM IV-TR or DSM-5 diagnostic criteria (Baio et al., 2014). In addition, Baio et al. determined that ASD is reported in all racial, ethnic, and socioeconomic groups and is about 4 times more common in boys than in girls. A study by Levy et al. shows that a diagnosis of Autism Spectrum Disorder does not usually occur in isolation of other developmental diagnoses. In fact, the rate of one or more non-ASD developmental diagnoses among those with ASD is 83% and the rate of one or more

psychiatric diagnoses is 10% (Levy et al., 2010). Although there is not a singular known cause of Autism Spectrum Disorder, research shows that ASD results from a combination of genetic, neurobiological, and environmental risk factors that lead to the diagnostic behavioral symptoms (Landrigan, Lambertini, & Birnbaum, 2012).

Suggested Tools for Management Perioperative ASD

Many researchers provided helpful suggestions for managing care for patients with Autism Spectrum Disorder in the perioperative environment. Notably, one group found that the most powerful tools for handling the challenges posed by ASD include listening to parents and caregivers, using simple strategies for success including Social Stories ™ and comfort items, and having a clinical practice guideline available at the institution (Taghizadeh, Davidson, Williams, Story, & Thomas, 2015). Another fairly simple intervention that has proven positive results is the act of "pre-screening" children for behavioral problems and preparing them for the new environment before the day of their procedure (Christiansen & Chambers, 2005). This research performed by Christiansen and Chambers (2005) notes that children can be screened via phone or at the routine preoperative clinical visit. The researchers indicate that the screening and visit should include a tour, play therapy, mock anesthesia induction, and family counseling. Encouragingly, a study by Arnold et al. (2015) found that the operative and postoperative experiences of children with ASD did not pose special challenges related to their behavioral diagnosis.

Trust of Parents and Caregivers. Some of the most valuable tools available for coping with patients with Autism Spectrum Disorder in the perioperative setting are the thoughts, opinions, and wishes of the child's parents or caregivers (Taghizadeh et al.,

2015). Taghizadeh et al. (2015) note that parents are to be considered the "experts" on their own children and to be trusted to know what disturbs or calms their child most. The researchers emphasize that talking to parents before the day of the procedure is ideal, so that staff can gain a good understanding of what the patient's needs are. Additionally, the Canadian Paediatric Society suggests that decision-making for all children and adolescents should be interdisciplinary and collaborative; treatment decisions should actively involve the family and even the child, when appropriate. ("Treatment decisions regarding infants, children and adolescents," 2004).

Preoperative Visits and Social Stories ™. Research points to the importance of a preoperative visit to make the child with ASD and their families more comfortable before the day of the scheduled procedure (Shah, 2014). Shah notes that it may be helpful for the institution to have a plan for readiness in caring for children with ASD, and elaborates by saying that although each child has unique and individual needs, a "hospital passport scheme" may be a beneficial way to guide these children through the perioperative experience with fewer poor outcomes. A hospital passport scheme, according to the National Health Service, is a tool used to help a person with a learning disability or developmental diagnosis be identified and cared for in the hospital (2015). This is a paper resource that can be attached to a hospital bed or kept near the patient to signal to the medical staff that the person belongs to a special subset of patients and may have certain communication or care needs related to their intellectual or developmental diagnosis (Learning Disabilities, 2015). Social Stories ™ are another tool that may effectively help children with ASD navigate the experience of their procedure (Kokina & Kern, 2010). Social Stories ™ are paper or digital documents used by people with ASD that describe a situation

or concept using relevant social cues, written language, and audio or video media (Karkhaneh et al., 2010). They can be implemented and studied before the actual event they depict to prepare a person with ASD for what will happen (Kokina & Kern, 2010). In a systematic review of how Social Stories ™ improved social skills in children with ASD, Karkhaneh, Clark, Ospina, Seida, Smith, and Hartling found that there were statistically significant benefits in many outcomes related to social interaction for patients with ASD (2010).

Premedication before Anesthesia Induction. The discussion of perioperative psychosocial interventions for children with Autism Spectrum Disorder frequently includes the suggested act of tailored anesthetic induction (Seid, Seid, & Sherman, 1997). Oftentimes, a premedication is used in patients that may have difficulty calmly and safely waiting for general anesthesia induction (Christiansen & Chambers, 2005). A prospective study by Elliott, Holley, Ross, Soleta, and Koh from 2018 notes that children with ASD had higher reported anxiety in the preoperative holding space than typically developing children. In addition, the literature states that children with ASD are more likely to have a non-standard experience with premedication in terms of type or route of medication (Arnold et al., 2015). Current medications used for premedicating pediatric patients before anesthesia include clonidine, dexmedetomidine, midazolam, and ketamine in varying routes of administrations and doses (Taghizadeh et al., 2015). While all patients, with or without ASD, may receive a premedication before general anesthesia, children with ASD are more likely to receive a premedication, and generally had poorer compliance in anesthesia induction (Elliott et al., 2018). Therefore, one of the main challenges in the preoperative unit is transitioning a child with Autism Spectrum Disorder from arrival on

the unit to anesthesia induction (Elliott et al., 2018). The research by Elliott et al. (2018) indicates that interventions, tools, and policies should be focused on this time period especially.

Perioperative Distractors. For many children with Autism Spectrum Disorder, distractors like games, music, toys, or personal items from home can and should be used in the perioperative environment to decrease anxiety (Seid et al., 1997). A more recent study explains that the use of tablet computers is also helpful in distracting anxious children with ASD from the often overstimulating and new environment of the perioperative area (Taghizadeh et al., 2015).

Staff Education and Preparedness. Because children with developmental disabilities may get frustrated by the hospital environment and therefore exhibit challenging and potentially dangerous behaviors for staff to handle**,** staff confidence in management of these patients and behaviors is paramount (Johnson, Lashley, Stonek, & Bonjour, 2012). The Johnson et al. study (2012) shows that online and in-person staff education decreased staff discomfort at caring for patients with developmental disabilities, and allowed staff to learn strategies for preventing and managing challenging behaviors exhibited by this patient population.

Strategies for Handling Challenging Behavior. There are many evidence-based methods for preventing and controlling challenging behavior posed by pediatric patients with Autism Spectrum Disorder. One study evaluated the effectiveness of a "coping kit" containing communication cards, a Social Story ™, and distraction toys used by nurses in a pediatric hospital caring for children with challenging behaviors (Drake, Johnson, Stoneck, Martinez, & Massey, 2012). In this evaluation, nurses found that the kits were effective for

decreasing patient anxiety and increasing cooperation during procedures. A systematic review by Johnson and Rodriguez (2013) gives many helpful recommendations. The first is to avoid overstimulation and confusion in caring for patients with ASD by using calm concrete language and avoiding sarcasm, teasing, and jokes. They also recommend using pictures rather than vocal language. Perhaps most importantly, they recommend remaining patient, reducing the number of tasks required of the patient, and using positive reinforcement and distraction. Johnson and Rodriguez also touch on the importance of not interrupting the self-stimulatory behaviors of children with ASD, as these behaviors are often ways to control anxiety in the child and may be helpful. They go on to discuss the value of Now/Then pictures, which prepares the child for a change in activity with visual prompts and rewards. Although there is a great deal more research on specific strategies for preventing and stopping challenging behavior, the focus on the methods above is adequate for this project.

Methods

Microsystem Assessment

A thorough assessment of the microsystem was performed by members of the team, who shadowed and observed each aspect of patient care within the system. The microsystem was considered the entirety of the perioperative area of the Outpatient Center of a large non-profit and state funded children's hospital in the San Francisco Bay Area, which included the preview clinic, preoperative unit, operating rooms, and post-anesthesia care unit (PACU). Because these units do not function in isolation of one another, for the purposes of this project they are considered one microsystem with many parts. In the Outpatient Surgery Center a full spectrum of general pediatric surgery options exist for

children who come in as patients. This includes minimally-invasive laparoscopic and endoscopic procedures as well as more specialized neuro and cardiothoracic surgery. Additionally, dental procedures under general anesthesia are performed for patients who may not tolerate traditional sedation at a dentist's office. The center is equipped with a complete surgical team and hospital staff. The purpose of the children's hospital is best revealed in their Mission Statement:

> The mission of [this hospital] is to ensure the delivery of:
>
> - The highest quality pediatric care for all children through regional primary and subspecialty networks;
> - A strong education and teaching program; a diverse workforce;
> - State of the art research programs and facilities and;
> - Nationally recognized child advocacy efforts

The hospital serves a large region that includes Northern California and beyond. No pediatric patient in the region is ever turned away for financial reasons. Because of this, the client population is very diverse in terms of socioeconomic status, race, and medical diagnoses. In 2017, 17.8% of patients seen in the perioperative unit were diagnosed with a behavioral diagnoses, which includes Autism Spectrum Disorder.

Professionals involved in the microsystem include nurses, nurse practitioners, anesthesiologists, surgeons, dentists, surgical technicians, medical translators, and a child life specialist. The nursing staff members have many roles, which include checking the patients into the preview clinic or the pre-operative unit, preparing the patients for the procedures, assisting in the operating room, and caring for patients in the PACU. The nurse practitioners run the preview clinic and provide pre-operative appointments in which

patients come in for a history and physical. Patients may also be oriented to the perioperative unit during their visit to the nurse practitioners. Surgeons, dentists, and anesthesiologists interact briefly with nurses and patients' families before and after the procedure to clarify the plan of care and provide a chance for patients and families to ask questions. The majority of their work is done while the patient is under anesthesia in the operating room; they are assisted by surgical technicians. Medical translators help to reduce the language barrier that often exists between patients, families, and medical staff. The translator is available both before and after procedures, and is a valuable resource for patients who do not speak English or are not comfortable speaking English when discussing medical procedures and other complex topics. Finally, a child life specialist is available in the preview clinic and in the preoperative unit to help ease the fear and anxiety for children having procedures. She interacts with each child on their developmental and skill level to prepare them mentally and emotionally for their procedure, and to clarify that they understand what is happening to the best of their cognitive ability.

Many processes make up the day-to-day flow of the microsystem. Included in this analysis are processes that may need alteration. These include transitioning children with Autism Spectrum Disorder from check-in to the point of anesthesia induction, communication between anesthesiologists and pre-operative nurses regarding premedications, and nurse preparedness for caring for a child with Autism Spectrum Disorder. Because children with ASD may need special resources and consideration, the processes in which they are involved are more complicated than for a typically developing child. For instance, a quiet and private room can be provided for a patient with ASD. Additionally, procedures scheduled early in the morning when the unit is quieter and the

patient is calmer may help the patient transition more easily. These tactics were noted during the microsystem assessment. One noted incidence of a broken process was regarding communication between anesthesiologists, nurse practitioners, and nursing staff regarding anesthetic premedication for the reduction of anxiety. A more streamlined or regulated process for recommending a premedication would have potentially reduced the tension caused by this failed process. Finally, lack of nurse confidence and preparedness in caring for children with ASD was observed during the microsystem assessment. Although nurses were interested in learning about how to care for children with ASD or another behavioral diagnoses, few felt that they had the tools they needed to do so. Although the child life specialist was helpful in crisis situations and with caring for children with behavioral diagnoses, she did not have formal training in caring for the specific population of children with Autism Spectrum Disorder.

Data Collection

All patient data collected by the team was collected free of patient identifying information from the eMRS by hospital staff members. It was then relayed to the project team through nurse administrators and hospital data scientists working with surgical services. Data on nurses was received from a group of students who worked on this project on the same unit in 2017.

Cost of Delay

In a 2017 survey of nurses, 55% reported that a behavioral crisis resulted in surgical delay, 28% reported that they felt prepared to handle a behavioral crisis, and 97% wanted specialized behavioral training. During 2017, there were an estimated 5,455 hours of surgical delay costing the hospital an estimated $80,515,800. Extrapolating this data to

account for cost of delay due to patients with behavioral diagnoses, it can be estimated that crises in patients with a behavioral diagnosis may have cost the hospital around $14,331,812.40.

Parent Questionnaires

Because the research depicts so clearly the need to involve parental thoughts and opinion into the care plan of children with Autism Spectrum Disorder, the team decided to incorporate a parent questionnaire (Appendix A) for all patient families in order to determine the needs of each patient. Although the questionnaire does not specifically mention Autism Spectrum Disorder or other behavioral diagnoses, it aims to prepare nurses and other professionals caring for the patient of any potential behavioral problems or solutions that would be helpful to know. The questionnaire was provided to parents and caregivers upon arrival to the check-in desk in the Outpatient Center. Some of the patients whose families took the survey were waiting for the preview clinic, while others were waiting for their actual procedure. The surveys were completed on paper while the families were physically nearby to the patients. They were offered in English and Spanish. To assess whether parents and caregivers felt that the questionnaire was helpful to them and their child, a Likert Scale survey was provided to them at the same time of the questionnaire (Appendix B).

Staff Education

Because a large portion of the nursing staff did not feel confident in handling challenging behaviors posed by patients with behavioral diagnoses included Autism Spectrum Disorder and expressed interest in having more specialized training on the subject, the team organized a perioperative in-service with a local non-profit, Juvo. Juvo

specializes in behavioral health services for children with Autism Spectrum Disorder and other special needs ("Services," 2018). They utilize the philosophy of Applied Behavioral Analysis (ABA) and other evidence-based methods to help their clients navigate daily life with their families and communities.

Staff toolkits were created by the team and explained during the Juvo in-service. This toolkit, as well as the at-a-glance paper for the unit are resources for nurses to use in preparation of caring for a child with Autism Spectrum Disorder (Appendices C & D). They include strategies for safely handling patient care with this population and concrete step-by-step guides for having positive patient interactions. There is also a Parent Toolkit available online and on the unit for families preparing for a visit with their child with ASD (Appendix E).

Results

Parent Questionnaire Results

The pilot implementation of the parent questionnaire was conducted in the Perioperative Admissions area of the Outpatient Center. Thirty-five families gave feedback on three randomly selected days (Appendix F). Data collected from the Likert Scale effectiveness surveys completed after the questionnaire stated that 72.7% thought staff was most likely better prepared to care for their child because of the questionnaire. The collected data also indicated that families were at least 66.7% positive across all metrics collected.

Staff Education

After the in-service provided by Juvo on April 18, 2018, responses were collected from nurses, technicians, and physicians working on the perioperative unit. Twenty-nine

members of staff participated in the in-service education, and 17% provided feedback on a written questionnaire (Appendix G). The general trend of the feedback showed that staff confidence in preparedness improved.

Implementation

The staff and family toolkits, as well as the at-a-glance document were implemented in the perioperative units and on the hospital's website. Feedback from the hospital's Family Advisory Council, the Nursing Leader and Quality Council, and the unit staff was positive.

Discussion

While the results from our studies proved largely positive results, there are other contributing variables that could explain the data.

Limitations of These Studies

Extrapolation of Data. In order to determine the delay time and cost of delay due to behavioral diagnoses, the team had to make some generalizations about the data available from hospital staff. The total number of surgeries discussed also included another outpatient surgery location. In addition, not all surgical delays are caused by patients problems; some surgical delays occur because of staff issues or unforeseeable events. Finally, we do not have enough information to know if the proportion of patients with a behavioral diagnosis caused the same proportion of delay time. In order to put the posed problem into the terms of financial loss, some liberties with the statistics were taken.

Parent Questionnaires and Surveys. Although the sample size of of 35 parent questionnaires is probably adequate to witness trends, there may have been some factors in the collection of data that led to false answers. Researchers were standing or sitting

fairly close to families as they filled out the questionnaires, and though every attempt to have the surveys remain confidential was taken, there may have been perceived pressure to please the researcher. In addition, older children who can read were often near to the parents as the questionnaire was being filled out about them. This could have interfered with parent answers. Finally, the Likert Scale used on the survey was possibly misinterpreted by some caregivers to be the opposite scale of what was written.

Staff Feedback. There was a very small amount of staff feedback data available after the Juvo in-service. Because only 17% of staff that attended the education event provided feedback, the positive data received is not strong.

Conclusion and Future Study

In order to better serve children with Autism Spectrum Disorder in the perioperative setting, implementation of resources and more widespread acceptance needs to occur in this unit. In the future, full integration of the parent questionnaire into the workflow of nursing staff in perioperative services is recommended, as well as integration in the electronic system already in use in the hospital. Care for children with ASD must continue to be specialized and unique. Future recommendations include more staff collaboration with Juvo, creation of a hospital passport system, and a sensory room or sensory kit. With increasing knowledge and data available on the population of pediatric patients with Autism Spectrum Disorder, more evidence-based tools must be sought after to continue providing the best care possible.

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Appendix A

Please fill out this form to let us know more about your child and how we can best provide care for your family.

Patient Name:_____ Date of Birth:_____

Parent/Guardian Name: _____ Phone: _____

How does your child communicate:

- ☐ Full Sentences
- ☐ Short Phrases
- ☐ 1-2 Words
- ☐ Sign Language
- ☐ Assistive Device: _____
- ☐ Other:_____

What tools do you use to help soothe your child?

- ☐ Quiet environment
- ☐ Rewards
- ☐ Books
- ☐ Games
- ☐ Support Items/Devices
- ☐ White Noise
- ☐ Other:_____

Does your child understand this upcoming procedure? ☐ Yes ☐ No ☐ Unsure

How have past hospital visits been for your child? (Check all that apply)

- ☐ Happy
- ☐ Fighting
- ☐ Easily Separated
- ☐ Calm
- ☐ Upset, but Cooperative
- ☐ Better with Parents
- ☐ Scared
- ☐ Uncooperative
- ☐ Distracted
- ☐ Other: _____

Has your child had anesthesia before? ☐ Yes ☐ No ☐ Unsure

If yes, did they need a premed (calming medication) in Pre-Op? ☐ Yes ☐ No ☐ Unsure

If yes, what was the name of the medication: _____

Which of the following are triggers for your child?

- ☐ Loud Noises
- ☐ Pain or discomfort
- ☐ Transitions
- ☐ Bright Lights
- ☐ Something is taken away
- ☐ New People

How does your child handle new environments? ☐ Good ☐ Fair ☐ Poor

What can we do to help you and your child have an easier time before, during, and after the upcoming procedure?

- ☐ Parent With Child
- ☐ Comfort Items
- ☐ Other: _____
- ☐ Distraction

Is there anything else you would like us to know? _____

Appendix B

Perioperative Questionnaire Feedback

Thank you for utilizing the perioperative questionnaire! If you have time, please take a moment to fill out this form and return it to staff check-in so we can improve its usefulness to staff and families.

Please mark an **X** for items 1-4 to record the strength with which you agree or disagree with the following statements.

Item	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. This questionnaire was easy to complete.					
2. This questionnaire helped staff understand my child's individual needs.					
3. This questionnaire accurately incorporated all relevant information needed prior to surgery.					
4. I am confident that staff are now better prepared to provide safe care for my child.					
Comments:					

Appendix C

Perioperative Services Autism Toolkit for Staff

How to Prepare for Your Patient's Visit To Ensure Safe & Effective Care

UCSF Benioff Children's Hospital Oakland

Table of Contents

Introduction & Overview

Autism, also known as Autism Spectrum Disorder (ASD), is a condition characterized by challenges with communication, social skills, sensory processing, and rituals or repetitive behaviors ranging from mild to severe. Children living with ASD may have a difficult time functioning outside of their comfort zone and can pose unique challenges in the perioperative setting. The objective of this toolkit is to give staff the resources and tools needed to guide patients with autism and their families through their experience at BCHO.

Although peri-operative visits can be anxiety-inducing and frightening for any child, they may be especially challenging for a child with ASD:

- Triggers may include bright lights, loud noises, unfamiliar textures, and new people.
- Physical expressions of confusion, anger, or fear can compromise patient and staff safety, resulting in delays in care.

Caring for children living with autism requires a customized care plan through the implementation of creative and appropriate tools. Remember, each child is an individual with unique needs and perspectives. With these resources, caregivers can surely build successful relationships with their patients and guide them safely through their procedures. The information in this toolkit can guide staff to provide better patient care to patients with ASD and their families.

Preparing for Patient Visits

The following preparatory measures should be taken to prepare for a child with ASD in periop:

- Parents, family, and/or caregivers:
  - Fill out the Parent Behavioral Questionnaire during their Preview Clinic visit or before pre-op
  - Use the Perioperative ASD toolkit to prepare their child for procedures
- Staff
  - notified of the upcoming arrival of a child with ASD or potential behavioral issues either from a Preview Clinic Nurse Practitioner, the referring physician/provider, or during the pre-op phone assessment
  - Utilize Parent Questionnaire results, sensory-friendly toys, coloring materials, reference materials, and visual aids to improve patient outcomes

Additional resources available to staff include:

- At-A-Glance Pamphlet:
  - Provides a quick referral regarding the information provided in this toolkit
- Parent Questionnaire:
  - Provides a place for parents to share with staff the expected behaviors and reactions of their children to hospital settings
  - Given to all parents prior to Pre-Op, regardless if the child has a diagnosis of ASD or not
- Parent/Family Toolkit
  - Provides information regarding the patient experience before, during, and after their stay in BCHO
- Social Story
  - Provides photos and descriptions familiarizing the patient with the upcoming periop experience prior to arrival

These resources should all be available in the unit, from the perioperative nurse educator, Child Life Services, or online.

Strategies for Managing Behavior

1. Say, Do, Show, Reward

The Say, Do, Show, Reward is effective in urging children with ASD to follow simple instructions.
Using the method:

- **SAY -** Use 2-3 word commands like *"Sit chair"*, or *"take temperature"*
- **DO -** Demonstrate the action on yourself, if appropriate
  - Example: Use the stethoscope on yourself so they see where it will be placed
- **SHOW -** Allow patient to perform the action and use the tools, if appropriate
  - Example: Have the patient use the stethoscope on themselves
- **REWARD -** If the patient displays desired behaviors, they may hold and play with the reward item
  - Allow the patient to choose one reward item between two options (a teddy bear or a tablet)

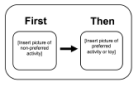
DOs and DON'Ts

- DO use a calm, low-toned voice, ending sentences with upward inflection
- DO focus on actions you want the child to take, instead of things you want them to stop
- DO allow the child ample time to process information and commands.
- DO NOT use articles or prepositions (in, on, your, my)
- DO NOT use time bound language (now, it's time to, later)
- DO NOT force eye contact or physical touch (let the child lead)

2. Behavior Contracts (First, Then)

Before asking a child to do something that they find unpleasant (such as taking their blood pressure), show them that they will get a reward for doing what you're asking.

- Use If / Then language (e.g. *"If you put on your pajamas, **then** you get to hold the teddy bear."*)
- For younger children, or those who have trouble communicating verbally, use a First / Then card like the example below.



3. Sensory Strategies

Lights, sounds, smells, and textures can be overwhelming, or even painful, to a child with ASD. These children can have trouble filtering "background" sensations. Instead, they experience everything and have more intense reactions to unpleasant sensations.

It can be difficult to understand which environmental stimulus is triggering a child's behavior. Each child has their own likes and dislikes, so it is important to ask the child's caregivers or refer to the **Parent Questionnaire** for potential triggers and calming strategies. It's often impossible to remove all triggers, but through proper preparation, optimal support can be given to the patient.

Limit…

- Bright, fluorescent lighting
- Mechanical sounds (machines beeping, phones ringing)
- Clothing with tags or pronounced seams
- Harsh-smelling chemicals
- Unnecessary equipment and clutter in exam rooms
- Number of staff in the room with the child at any one time
- Amount of time child has to wait

Encourage…

- Use of "fidget toys" or toys with soft, squishy textures
- Sunglasses, earphones, or earplugs if environment cannot be modified

- A visual schedule rather than verbally telling the child the order of events
  - Allow predictability by following the order of the social story
  - To ease transitions, remind child of the next event on the schedule before it occurs
- Movement breaks every 10-15 minutes
- Reorient an overstimulated child to where their body is in space by encouraging rocking, deep massage, up-and-down movements like jumping jacks, or bouncing on a yoga ball

4. Recognizing and Responding to Stress

When a child is "acting out" in a way you don't want, first consider why. Almost always there is an antecedent or trigger which may not be initially obvious (often from a prior experience). Since many children with ASD have trouble communicating verbally, they may be showing nonverbal signs of stress. They may also have trouble self-regulating or calming themselves down and will need your help. It's important to recognize these signs and to work with the families to minimize the child's stress.

Signs of Stress

- Running away
- Withdrawing into own world
- Covering eyes or ears
- Constant fidgeting, pulling, twisting, or chewing
- Hand flapping
- Stiff, awkward, or unbalanced posture
- Regressive behaviors (e.g. sucking thumb or wetting pants when not typical)
- Increased frequency and intensity of repetitive behaviors (e.g. counting, humming, tapping, switching lights on and off)
- Deep moans
- Self-injuring behaviors (e.g. hitting head, slapping self, biting self, scratching, flailing, eating non-food items)
- Aggressive behaviors (e.g. kicking, screaming, hitting, biting)

Address the Stress

- Remove any obvious stressful triggers (e.g. dim bright lights, move child to a quiet area, etc.)
- Ignore undesired behaviors and reward desired behaviors.
  - Ignore the child when they are acting out and only give attention and praise when they start to calm.
- Children may be used to getting attention for the undesired behavior so *they may escalate before they calm down.*
- Ignore the behavior, not the child.
  - Immediately intervene if they are engaging in unsafe behaviors.
  - Reward them as soon as you see desired behavior, otherwise they won't understand what you want and will continue to escalate.
- Protect self and other patients from injury

5. De-Escalation: Reactive Strategies

Once a patient has already started to display signs of anxiety, stress, or an impending meltdown, utilize the following strategies to help calm them down.

- Be familiar with the **Parent Questionnaire** results, and what signs of stress or impending aggression the patient is known to display.
- Do not crowd the patient. Provide them with ample space, as long as it is safe to do so. Some patients have a limit to the number of people they can handle at one time, so limit the number of staff interacting with the patient.
- Using the "Say-Do-Show-Reward" method, divert unwanted behaviors and distract the child with their favorite item. Before giving the item to the child, ask them to do a simple task (e.g "Clap your hands!") while demonstrating the task. Once they do the task, praise the child and immediately give them the item.
- Use short 1-3 word sentences. Utilize pictures and written words, in accordance with patient verbal ability, as much as possible.
- Stay calm and be mindful of your tone of voice, posture, and other nonverbal communication (such as gesturing).
- Allow the patient to make choices between 2-3 options.
- Limit noise, when possible, and dim the lights or avoid bright lights if safe.
- Use the "First-Then" Approach and pictures to explain what the patient has to do in order to receive their reward.

Acknowledgments

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The authors would like to give special thanks to the following internal and external collaborators.

UCSF Benioff Children's Hospital Oakland

- Perioperative Services
  - Scout Hebinck, RN-C, MSN, Nurse Educator
  - Perioperative Staff
  - Preview Clinic (PAT) Staff
  - Anesthesia Team
- Child Life Services
  - Hania Thomas-Adams
- Mental Health & Child Development
  - Shanti Gooden, MD
  - Monifa Willis, PMHNP-BC
- Kaizen Operations Team
  - Susan Martinez, Director
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  - Mao Li, Clinical Informatics Specialist

External Collaborators

- Juvo Autism & Behavioral Health Services
  - Kristin Ojala, MA, BCBA
- Valley Children's Hospital, Fresno CA
  - Tana Leon-Toscano, Peri-Op Educator

*Marissa Carapinha, Linda Gorostieta, Paige McCann, Kelsey Morton, Sabrina Young-Koii, Ian Fong, Heather Ford, Sandra Lieu, Charlene Noce, and Erin Scheller

Appendix D

5 Strategies for Approaching A Patient with ASD

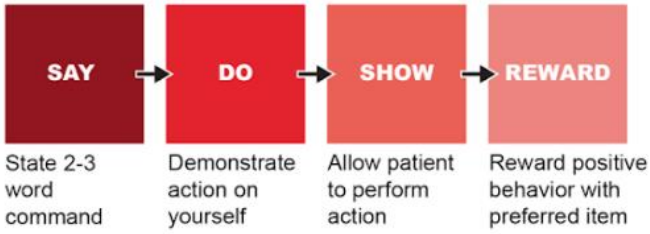
Parents Keep the parents involved as much as possible and encourage them to stay. They know their kids the best! Encourage preferred home activities to be with the child.

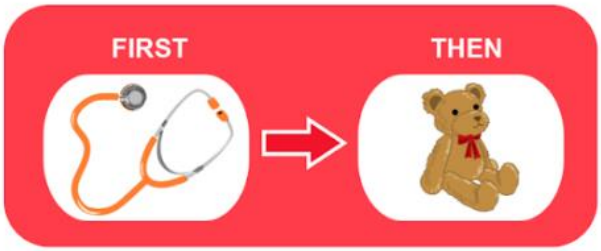
Language Use calm, concrete language and avoid sarcasm or jokes, use pictures & diagrams.

Behavior Approach the patient gently and be patient. Reduce the number of commandsand cluster nursing interventions.

Environment Create a calm environment, decrease stimulation, use quiet rooms, dim lights and have one staff member with the patient at a time

Address Stress Ignore undesired behaviors and reward desired behaviors, let patients continue with their self-stimulatory activities, i.e. rocking, up/down motions.





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Appendix E

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Perioperative Autism Toolkit

A Guide for Parents:

How to Better Prepare your Child for their Upcoming Surgery

Follow me to page 4 to learn more about what to expect the day of surgery.

Inside

Always remember...

"if you've met one person with autism, you've met one person with autism."
(Autism Speaks)

"Children on the spectrum have a high need to control their environment, and advance preparation can help ease their anxiety" -A parent on the Family Advisory Council

Autism Spectrum Disorder (ASD), also known as autism, is a brain disorder that can affect communication, social skills, sensory processing and often results in rituals or repetitive behaviors. Due to these characteristics, children living with autism may have difficulty adapting or functioning in environments outside of their comfort zone. Naturally, these children function better with a well-established routine where they know what to expect, step-by-step.

Surgery can be uncomfortable and frightening for any child, but especially for children with autism. The new environment, bright lights, loud noises, unfamiliar textures, and the interactions with new people can be stressful and overpowering. As a result, children living with autism may act out when overwhelmed. To better serve children living with autism needing surgery, this toolkit is designed to help you and your child have a more comfortable and successful visit at UCSF Benioff Children's Hospital Oakland (BCHO).

To make the surgical visit as successful as possible strategies can be implemented to ensure that everyone is well supported.

The best way to ensure that surgery day runs smoothly for a child living with autism is preparation, preparation and more preparation

Repeated Exposure

Repeated exposure to uncomfortable situations can make new experiences easier for children living with autism.

- Pretend play with doctor materials.
- Showing the child pictures of medical equipment.
- Tour the actual setting before the day of surgery.

The more you know, the better you will feel. What to do prior to surgery.

To create a customized, individualized care plan staff should be notified in advance of the arrival of a child with autism. This can be done when the child is seen at the Preview Clinic or during the pre-operative phone screening if the child is unable to make it to the Preview Clinic. To better assist your child you will be asked a series of questions to allow staff to adjust the perioperative environment based on your child's individual needs.

Other strategies that can be beneficial in preparing your child for surgery include asking for a tour of the perioperative area and obtaining a set of hospital pajamas to take home that they can wear the day of surgery. Lastly, families will be given materials such as a social story, visual schedules, and this toolkit to better prepare for surgery.

Social Story: A social story can help a child understand events that will occur. Social stories use a variety of photos and simple language to describe a situation. This allows a child to visualize the expected steps that will occur on the day of surgery. Theses photos are most effective when showed to a child *at least one week in advance.*

Visual Schedules: Pictures can be used to help a child living with autism understand the sequence of events. Visual schedules can allow children to know what steps have been completed and what steps remain.

Continued from page 1

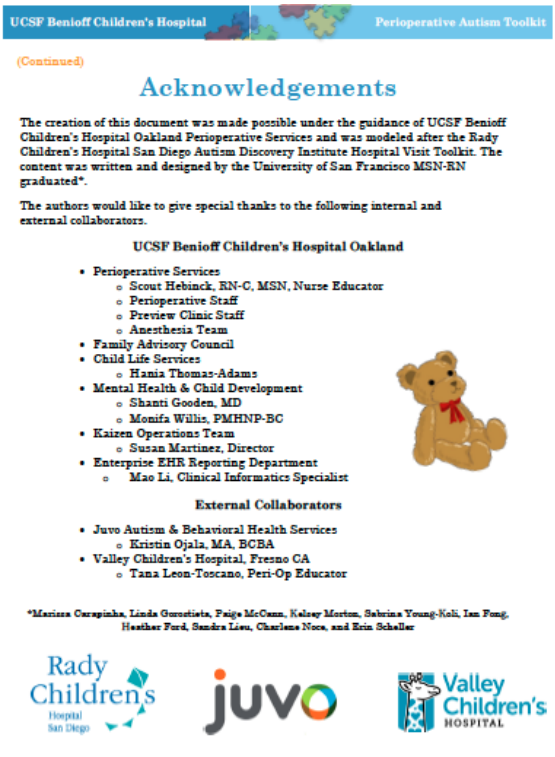
The day has finally arrived: What to expect the day of surgery.

- In the outpatient building lobby, walk straight from the front desk and take the elevators up to the 3rd floor.
- Register with the clerk at the Surgery Registration window.
- Wait to be called by a pre-operative nurse to be taken to the pre-operative area. *The role of the pre-operative nurse is to receive and prepare the patient for surgery.*
- In the pre-operative area, you will meet your child's doctor, the operating room nurses, and the anesthesiologist. Each provider will ask you a series of questions to ensure safe and effective care.
- If necessary, the child life specialist may be involved in your child's care. *The role of the child life specialist is to assist with preparing patients for medical procedures by using age-specific tools and help support children by developing strategies such as imagery, distraction and relaxation to reduce anxiety associated with surgery or hospitalization.*
- After surgery, a staff member will notify you when your child is finished with surgery. Your child will be transferred to the post anesthesia care unit (PACU), also referred to as the recovery room, where the PACU nurse will care for them. *The role of the PACU nurse is to help your child as they wake up from anesthesia.*

After surgery your child may still be asleep or be disoriented due to anesthesia. Make sure to have their favorite items to greet them with.

Last Minute Reminders:

1. Remember to dress your child in the hospital pajamas.
2. Bring a few of your child's favorite things (e.g. iPad, favorite stuffed animal, blanket etc.)
3. Do not bring other children to the hospital on the day of surgery, if possible.
4. A novelty toy, or special toys your child does not play with often, is a good idea to motivate the child.



UCSF Benioff Children's Hospital | Perioperative Autism Toolkit

(Continued)

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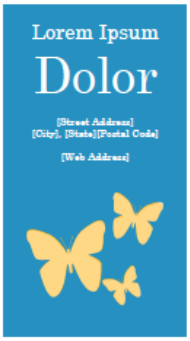
Rady Children's Hospital San Diego | juvo | Valley Children's Hospital



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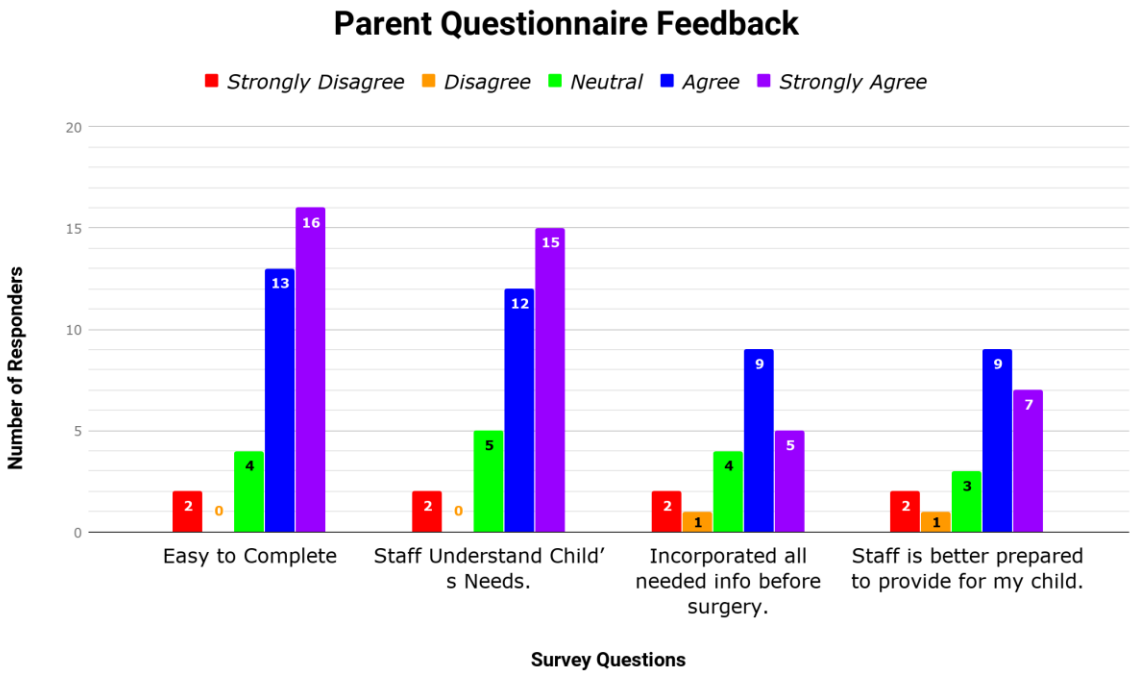
Appendix F


Parent Questionnaire Feedback
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Number of Responders
20
15
10
5
0
2
0
4
13
16
2
0
5
12
15
2
1
4
9
5
2
1
3
9
7
Easy to Complete
Staff Understand Child's Needs.
Incorporated all needed info before surgery.
Staff is better prepared to provide for my child.
Survey Questions

Appendix G

Item (n=5/29)	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Have you ever encountered or cared for a child with a behavioral issue?	-	**2**	-	-	-
Prior to the in-service, I received specialized training for patients with ASD.	-	**2**	**2**	1	-
I have behavioral management tools available to me for the care of patients with ASD.	-	1	**2**	**2**	-
I am familiar with common de-escalation techniques and methods to calm patients with ASD.	-	1	**2**	**2**	-
I am confident and better prepared to provide safe care for an overstimulated and aggressive patient.	-	-	1	**2**	**2**
I plan to utilize the tools I learned about in today's in-service in my clinical practice.	-	-	1	**2**	**2**
This content was current and relevant.	-	-	-	**3**	2
The objectives could be achieved using the content provided.	-	-	-	**3**	2
This was an effective method to learn this content.	-	-	-	**3**	2

Rows 2-5 describe familiarity with skills prior to in-service. Rows 6-10 describe improvement in skills after in-service. Bolded numbers represent most common responses for each question.